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Submission to the Australian Law Reform Commission on the Review of the Family Law System – Issues Paper

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1 Introduction

We thank the Australian Law Reform Commission for the opportunity to make a submission on the *Review of the Family Law System—Discussion Paper*.

Intersex Human Rights Australia (IHRA) is a national intersex-led organisation that promotes the human rights (including the bodily autonomy) of people born with intersex variations. Formerly known as Organisation Intersex International (OII) Australia, IHRA is a not-for-profit company, with Public Benevolent Institution (charitable) status: <http://ihra.org.au>. This submission has been written by Morgan Carpenter, Co-Executive Director, and Aileen Kennedy, board member, with input from the board and members of IHRA. Please contact morgan.carpenter@ihra.org.au for further information or inquiries.

In this submission, we respond to the following questions in the Discussion Paper:

Question 9–1

In relation to the welfare jurisdiction:

Should authorisation by a court, tribunal, or other regulatory body be required for procedures such as sterilisation of children with disability or intersex medical procedures?

What body would be most appropriate to undertake this function?

In what circumstances should it be possible for this body to authorise sterilisation procedures or intersex medical procedures before a child is legally able to personally make these decisions?

What additional legislative, procedural or other safeguards, if any, should be put in place to ensure that the human rights of children are protected in these cases?

We also respond to (and reject) the following suggestions for reform raised in paragraph 9.107:

- *adoption of a more inquisitorial approach;113*
- *introduction of multidisciplinary tribunals with expertise in medicine, psychology and social work to consider these matters;114*

The former proposes incremental change, rather than the systemic reform and human rights framework we believe are necessary. The latter represents the status quo.

2 Recommendations

IHRA is committed to processes which will protect the human rights of people born with variations of sex characteristics and persons with disabilities, including infants, children, adolescents and adults. In line with the *Darlington Statement* and the *Yogyakarta Principles plus 10*, IHRA recommends that

1. All deferrable interventions which alter the sex characteristics of infants and children undertaken before their ability to consent on their own behalf should be prohibited. This prohibition should be embedded in legislation.
2. All non-deferrable interventions which alter the sex characteristics of infants and children undertaken before their ability to consent on their own behalf should be identified as notifiable medical treatment outside the scope of parental consent and requiring oversight from an independent oversight body.

3. The independent oversight body should operate within a human rights-affirming framework, with effective participation by human rights experts, child rights experts, disability and intersex community organisations. It should be tasked with, where appropriate, determining whether or not medical interventions are necessary and non-deferrable.
4. In relation to adults with disabilities, including those born with variations in sex characteristics, provision must be made to facilitate supported decision-making on an equal basis with other adults. Intersex and disability peer and systemic/individual advocacy organisations should be resourced to assist in these matters.
5. To ensure adherence and transparency with these provisions, the independent oversight body must be notified, post facto (after the event), of details of all cases involving either minors or adults with supported decision-making where informed consent and/or urgent non-deferrable medical necessity have been asserted.
6. In line with Article 12 of the Convention on the Rights of Persons with Disabilities, minors must be given support to develop and exercise legal capacity. In the absence of capacity of the minor, parents must be provided with robust information and access to peer-support and advocacy groups.

2.1 Current Regulatory Mechanisms

Regulation of medical interventions on minors with intersex variations and minors with disabilities urgently needs to move away from a medicalised framework and perspective and ensure that human rights protections are central to any oversight process and body. This requires that the oversight process is embedded in hard law rather than soft law regulatory processes.

To date, approval and consent processes have relied on medical professional self-regulation combined with judicial oversight in select instances. These processes have failed to safeguard the human rights of infants and children born with intersex variations. The existing framework, largely dependent on self-regulation, has failed to safeguard the human rights of infants and children born with intersex variations.

Within the existing framework of self-regulation, the recommendation of the authoritative¹ clinical consensus statement² was that expert multidisciplinary medical teams must be organised to develop diagnostic and treatment strategies based on current and up-to-date clinical knowledge. According to most published guidelines and clinical statements, this recommendation has been adopted in Australia.³ Individual case management plans, including diagnoses and treatment plans, is purportedly developed and implemented by multidisciplinary teams in close consultation and with fully-informed consent of parents. Among the issues to be determined by these teams is the issue of whether the proposed treatments are therapeutic.⁴

This issue is significant in medico-legal terms, since non-therapeutic medical interventions are likely to fall outside the scope of parental authority, and require court authorisation. Judicial oversight is

¹ Authoritative within the clinical paradigm.

² Peter A. Lee et al, 'Consensus Statement on Management of Intersex Disorders' (2006) 118(2) *Pediatrics* e488.

³ See, for example, Victoria Department of Health, 'Decision-making principles for the care of infants, children and adolescents with intersex conditions' (2013).

⁴ *Ibid.*

required where the proposed medical interventions are identified as non-therapeutic, invasive, irreversible, and where there is a significant risk of making the wrong decision and the consequences of a wrong decision would be grave and serious.⁵

2.2 Self-Regulation

2.2.1 Multi-disciplinary teams

Little statistical information is available on historic and current medical practices, though we are given to understand from discussions with clinicians that individual multidisciplinary teams know very little about the actual practices of other teams, and a high degree of variability in practices was reported to the Senate in 2013.⁶ This means that assurances of change to clinical practices in one hospital should not be taken to imply national consistency. Factors driving this variability may include multidisciplinary team leadership, clinician specialism, age and gender, personal dispositions and beliefs about concepts of normality, sex and gender.⁷ Morgan Carpenter comments:

Reviewing the evidence from both public and private submissions, Senators in that inquiry reported that ‘there is no medical consensus around the conduct of normalising surgery’. Indeed, this statement is reflected in literature and personal communications with clinicians who are able to make claims about their work and that of their own teams, but who otherwise acknowledge great variation in practices within hospitals, between hospitals, and between jurisdictions, often determined by the beliefs of the clinician with whom parents have first contact...

While the 2006 ‘Consensus Statement’ promoted the concept of multidisciplinary teams, Sarah Creighton has pointed out that their existence is no guarantee of changed clinical practices when they may be led by, and for, surgeons committed to early intervention and no credible non-surgical pathways yet exist. Psychological support for families and individuals remains marginalised with patchy availability.⁸

Georgiann Davis comments:

Medical authority over intersex conditions was also reasserted by advocating for and implementing medical management “teams” that would consist of various “experts” on intersex conditions... In the face of challenged medical authority, medical professionals are able to reclaim and reassert their positions as experts by operating in teams. At the same time, they are able to minimize any potential liability for hormonally and/or surgically treating intersexuality... While DSD medical management teams are allegedly now operating in teams with expertise from across professions, those from psychiatry are typically less

⁵ *Secretary, Department of Health and Community Services v J.W.B. and S.M.B. (Marion’s Case)* [1992] CLR 175.

⁶ Community Affairs References Committee, Senate of Australia 2013

⁷ Georgiann Davis, ‘“DSD is a Perfectly Fine Term”: Reasserting Medical Authority through a Shift in Intersex Terminology’ in P McGann and D M Hutson (eds), *Sociology of Diagnosis* (Emerald Group Publishing, 2011) vol 12, 155-182; Georgiann Davis, *Contesting Intersex: The Dubious Diagnosis* (New York University Press, 2015); Welmoed Reitsma et al, ‘No (Wo)Man Is an Island—The Influence of Physicians’ Personal Predisposition to Labia Minora Appearance on Their Clinical Decision Making: A Cross-Sectional Survey’ (2011) 8 *Journal of Sexual Medicine* 2377.

⁸ Morgan Carpenter, ‘The “Normalization” of Intersex Bodies and “Othering” of Intersex Identities in Australia’ in Jens Scherpe, Anatol Dutta and Tobias Helms (eds), *The Legal Status of Intersex persons* (Intersentia, 2018) 445–514.

involved. Their exclusion makes sense because psychiatrists are less likely than surgeons to hold essentialist beliefs about sex, gender, and sexuality. Instead, psychiatrists are likely to see intersexuality as a social phenomenon, 'or at the very least, a shared medical-cultural phenomenon'⁹

The Human Rights Watch/interACT report found similar issues:

One of the main problems within DSD teams, some practitioners told Human Rights Watch, was the divergent views from different disciplines of medicine, and the power structures that privileged surgeons' opinions and advice to parents. While DSD team members interviewed repeatedly cited psychosocial reasons for performing genital surgeries on infants, and reported that mental health services were made available to parents as part of their decision-making process, some mental health providers emphasized that their input was rarely valued or utilized (2017).¹⁰

Timmermans and others comment on clinical attempts to respond to reform:

Due to their epistemic advantages and the presentation of surgery as a solution, clinicians boost their professional authority by strategically deploying uncertainties to steer the decision-making process... the profession has been able to selectively appropriate challenges to its jurisdiction.¹¹

While clinical guidelines as part of the evidence-based movement aim to rationalize decision making and clinical practice, clinicians still exert professional autonomy over the decision of whether and how to implement such guidelines, eroding much of the homogenizing effect of these standards.¹² Many reform attempts are thus weakened by discretion and autonomy inherent to professional medical power. In other words, "professionals may interpret and implement patient-centred care in self-serving ways".¹³

The Family Court judge in the case *Re: Carla* heard from three members of the multi-disciplinary team for the child. While we agree that children should be seen by staff working within a multi-disciplinary team, to ensure that any necessary treatment meets minimum technical standards, such teams do not intrinsically protect the human rights of the child. Indeed, 2006 guidelines by the Accord Alliance, recommending multidisciplinary teams, stated:

⁹ Davis, "'DSD is a Perfectly Fine Term": Reasserting Medical Authority through a Shift in Intersex Terminology', above n

¹⁰ Human Rights Watch and InterAct, 'I Want to Be Like Nature Made Me": Medically Unnecessary Surgeries on Intersex Children in the US' (2017)
<https://www.hrw.org/sites/default/files/report_pdf/lgbtintersex0717_web_0.pdf>.

¹¹ Timmermans, Stefan et al, 'Does Patient-Centered Care Change Genital Surgery Decisions? The Strategic Use of Clinical Uncertainty in Disorders of Sex Development Clinics' [2018] *Journal of Health and Social Behavior* 002214651880246 <<http://journals.sagepub.com/doi/10.1177/0022146518802460>>

¹² Ibid.

¹³ Ibid

Although dedicated multidisciplinary teams which focus on patients' psychosocial well-being may be more likely than alternatives to provide optimal care, **a dedicated multidisciplinary team is neither a guarantor of nor a necessity of patient-centered care for DSDs.**¹⁴

The Human Rights Watch/interACT report states:

the establishment of DSD teams, while a positive development in that it has de-centralized decision making, has not addressed the roots of the problem—that parents are not getting full information and unbiased advice about surgical procedures, and that medically unnecessary surgical procedures that carry significant risk of harm continue to be presented as legitimate options (2017).¹⁵

Faced with a paediatric urologist in a multidisciplinary team meeting, parents Eric and Stephani Lohman have described how they were offered two choices, both involving surgery when their child was aged six months (Lohman, Lohman, and Davis 2018, 87–88). When questioned by the Lohmans on the lack of a non-surgical alternative, the surgeon “would not recommend that option”:

Other participants in the team meeting “were avoiding eye contact ... It seemed that the design of the DSD team had a limitation, whereby if no one is willing to challenge the surgeon in the room, then the team is merely there to serve him or her with an audience.”¹⁶

Multidisciplinary teams must operate within a framework that respects and affirms children's human rights, as described in statements by UN Treaty Bodies and the Office of the High Commissioner for Human Rights (Human Rights Committee 2017; Committee on the Elimination of Discrimination against Women 2018; Office of the High Commissioner for Human Rights et al. 2016; K. Sandberg 2018, 2015)

2.2.2 Determining Whether Medical Interventions Are Therapeutic

Medical professionals claim the expertise and insight to determine whether or not a specific intervention is therapeutic or non-therapeutic,¹⁷ meaning that they have positioned themselves as gatekeepers on whether or not court authorisation is required.

Medical interventions on intersex children are argued by clinicians to be in the best interests of children for a range of reasons,¹⁸ but primarily because they confer therapeutic value. However, the concept of therapeutic treatment is poorly defined and relies on unexamined and untested cultural assumptions. In

¹⁴ Consortium on the Management of Disorders of Sex Development, *Clinical Guidelines for the Management of Disorders of Sex Development in Childhood* (Intersex Society of North America, 2006). 1

¹⁵ Watch and InterAct, above n

¹⁶ Eric Lohman and Stephani Lohman, *Raising Rosie: Our Story of Parenting an Intersex Child* (Jessica Kingsley Publishers, 2018). 88-89

¹⁷ Department of Health, above n11, 21.

¹⁸ For example, S. M. Creighton, 'Long-term outcome of feminization surgery: the London experience' (Pt Blackwell Science Ltd) (2004) 93 *BJU International* 44. lists the following reasons that genital surgery should be performed: A more stable development of gender identity; A better psychosexual and psychosocial outcome; A relief of parental anxiety; Provision of a vaginal introitus for psychological relief; and menstruation and intercourse in adolescence and adulthood¹⁸

Marion's Case, the majority expressed some reluctance to adopt this distinction, but nevertheless did adopt it

But first it is necessary to make clear that, in speaking of sterilization in this context, we are not referring to sterilization which is a by-product of surgery appropriately carried out to treat some malfunction or disease. We hesitate to use the expressions "therapeutic" and "non-therapeutic", because of their uncertainty. But it is necessary to make the distinction, however unclear the dividing line may be.¹⁹

The notion of therapy and therapeutic treatment is slippery and malleable. Once an issue or problem has been medicalised, then medical treatment in response to that problem is marked as therapeutic. What appears to be, in medical rhetoric, a straightforward biomedical evaluation is riven with normative evaluations and unexamined assumptions. The Australian healthcare system appears to regard medical interventions on intersex infants and children as unambiguously therapeutic due to parental distress and potential psychosocial stigma, even when they take place on healthy intersex bodies, or where clinical evidence supports monitoring gonads, even though such interventions contravene human rights norms established by multiple UN Conventions and the conclusions of a Senate inquiry.

Kerridge, Lowe and Stewart argue that

the therapeutic/non-therapeutic distinction has completely broken down ... The distinction fails to tell us why some treatments need court approval and others do not... The better approach would be to jettison the distinction altogether and to work from an established list of treatments that require approval.²⁰

As noted in the Darlington Statement, 'Distinctions between "therapeutic" and "non-therapeutic" interventions have failed our population.'²¹

A particular source of contestation over whether medical interventions on minors born with variations of sex characteristics are in their best interests is the extent to which purportedly clinical decisions are imbricated with non-medical values. In other words, social, political and cultural considerations are cloaked in medical, health-related or clinical justifications. This means that those considerations and values are constructed as scientifically proven and are largely unexamined. They are presented as biomedical facts that are beyond challenge. As noted in the Report of the Senate Committee:

The committee is aware of a risk ... that clinical intervention pathways stated to be based on probabilities of cancer risk may be encapsulating treatment decisions based on other factors, such as the desire to conduct normalising surgery ... Treating cancer may be regarded as unambiguously therapeutic treatment, while normalising surgery may not. Thus basing a decision on cancer risk

¹⁹ *Secretary, Department of Health and Community Services v J.W.B. and S.M.B. (Marion's Case)* [1992] CLR 175.

²⁰ Ian Kerridge, Michael Lowe and Cameron Stewart, *Ethics and Law for the Health Professions* (Federation Press, 3 ed, 2009).

²¹ Androgen Insensitivity Syndrome Support Group Australia et al, 'Darlington Statement' (2017) <<https://darlington.org.au/statement.>>. 16

might avoid the need for court oversight in a way that a decision based on other factors might not. The committee is disturbed by the possible implications of this.²²

This form of encapsulation, whereby non-therapeutic considerations are entangled and interwoven with factors that appear unambiguously medical, is common within the clinical literature and also emerges in the legal discourse such as the case law.²³

The therapeutic value of genital normalising surgery is strongly contested, both within the medical establishment and within the intersex community. There were proposals by clinicians for a moratorium on early surgical normalisation as early as 1998.²⁴ There are many grounds on which claims about the therapeutic value of medical interventions are challenged. These include the paucity of robust evidence to support therapeutic claims; the emergence of contradictory evidence; the pathologisation of intersex bodies; heavy cultural investment in stereotypical and sexist beliefs about the sex binary; the naturalisation of the sex binary; the failure to give serious weight to gender identity before irreversible medical interventions are performed; emerging understanding of the extensive variability in clinical practice; the lack of unambiguous standards against which the 'abnormality' of intersex bodies can be assessed and 'normalised'; and the outpouring of reports of pain, trauma and suffering by those with lived experiences of medical interventions.

The consensus statement and similar literature promote a rhetoric of caution in identifying the parameters of therapeutic versus non-therapeutic interventions. However, the sheer numbers of procedures performed, including genital normalising surgeries with dubious therapeutic justification, suggests a different picture. The fact that all but eight such interventions have been deemed therapeutic and not requiring court authorisation indicates that the process by which decisions are made, including decisions about whether proposed procedures are therapeutic, are not exercised cautiously and with critical consideration for ethical concerns or human rights protections.

The majority in *Marion's Case* note that where a particular non-therapeutic medical procedure has been medicalised to a high degree, two key concerns emerge: First, the medical profession, like any other profession, has actors who 'act with impropriety as well as those who act bona fide but within a limited frame of reference.' Second, some procedures carried out by doctors are not merely medical issues. For example, 'the consequences of sterilization are not merely biological but also social and psychological.'²⁵ A 2001 report commissioned by the Australian Human Rights Commission into sterilisation of intellectually disabled women and girls reinforces this reading of *Marion's Case*:

²² Committee, Parliament of Australia, (2013). 91-92

²³ See, for example, *Re Carla (Medical Procedures)* [2016] FamCA (20 January 2016)., where the purported cancer risk is cited as the basis for the procedure, but an extensive range of non-medical considerations are constructed as interlinked with the gonadectomy.

²⁴ Kenneth Kipnis and Milton Diamond, 'Pediatric Ethics and the Surgical Assignment of Sex' (1998) 9(4) *Journal of Clinical Ethics* 398.

²⁵ *Secretary, Department of Health and Community Services v J.W.B. and S.M.B. (Marion's Case)* [1992] CLR 175. 250.

Doctors play a central role in what is not just a medical decision, but absolute faith in the integrity of all medical practitioners is not warranted; it is possible that parents, other family members, and carers may have conflicting interests which would influence their decision.²⁶

There is concern that in some case the medical profession can become overly invested in particular paradigms of treatment, and may 'act bona fide but within a limited frame of reference'. Furthermore, when dealing with medicalisation of very young children there is a danger that the conflicting interests of parents and care-givers will be given primacy over the interests of children. The conflicting interests that will be relevant in the context of intersex minors are a parental fears about bullying and discrimination against children with atypical bodies; deep and unexamined cultural investment in a rigid concept of binary sex; and disinclination to consider future sexuality and identity as being equally or more important than childhood experiences.

This is even more likely to occur where there is a culture of conflation between medical and non-medical issues – where the consequences of the procedure are 'not merely biological but also social and psychological'. Medical treatment of intersex children shares these salient features. Variations in sex characteristics have been medicalised to a great degree. As noted in the report of the Senate Committee, '[t]he concern expressed by the intersex community that sex differences are pathologised sits at the heart of the inquiry'.²⁷ Given the extensive criticisms and concerns raised about the treatment protocols over the last 30 years, absolute faith in the medicalised framework is unreasonable. The issues around medical interventions are not merely medical or biological issues, but have profound social and psychological meanings.

Given the multiplicity of medical interventions and the frequent need for a single intervention to be repeated or repaired, it is clear that, since the special medical jurisdiction was created in 1992, there have been literally thousands of medical interventions performed on intersex children.²⁸ The therapeutic status of many or even most of these interventions is contested; most are invasive and irreversible; and many present a serious risk of the wrong decision being made, with grave consequences.

However, only eight such procedures have been performed on the basis of court authorisation. Why these eight cases, which represent a very small proportion of procedures, were selected as requiring court authorisation (and by whom) is entirely unclear. It seems likely that the medical experts involved in treating intersex children have driven the medico-legal strategy. This suggests a deliberate policy of directing the judicial and legal regulation of medical interventions by cherry picking cases that are most likely to obtain approval and by cherry picking the medical evidence which is relied on. It also appears that

²⁶ Susan Brady, John Britton and Sonia Grover, Australian Human Rights Commission, *The Sterilisation of Girls and Young Women in Australia: Issues and Progress*, Report No (2001).

²⁷ Committee, Parliament of Australia, (2013).108 [5.63].

²⁸ Carpenter, above n

Queensland is disproportionately responsible for relevant Family Court cases, indicating differences in disposition towards judicial oversight in different jurisdictions.²⁹

It is untenable for the lawfulness of medical interventions on intersex children to continue to be self-regulated by the medical profession. This power has long been exercised without restraint or due consideration for the human rights of intersex people.

2.2.3 Judicial Oversight via the Special Medical Jurisdiction of the Family Court

The second layer of regulation within the current scheme of oversight is the requirement for Court authorisation for medical procedures which fall outside the scope of parental consent. This regulatory framework has also failed to safeguard the rights and interests of intersex infants and children.

The Family Court system has not understood the intersex population, nor the nature of procedures in cases that it has been asked to adjudicate. The Family Court cases approving medical procedures performed on intersex children are characterised by a consensus among the parties that the proposed procedures are in the child's best interests. In each of the 8 cases concerning intersex children which have been heard by the court, the respondent explicitly supported the application, meaning that there was no testing of or challenge to the application or evidence supporting it. In each case, either the hospital, health authority, mother, father or some combination acted as applicant and respondent. In this sense each of the respondents is a respondent in 'name only'.³⁰

The special medical jurisdiction has conferred responsibility on the Family Court to determine whether proposed interventions are in the best interests of the child. However, the court has not provided critical independent scrutiny. Instead, the Court appears to have been captured by a paradigm of pathologisation and a belief that bodies should conform as closely as possible to narrow and rigid sex and gender norms.

The failure in *Re Carla* to consider relevant medical evidence on gender identity development available on record and explicitly cited in the judgment in *Re Sally* indicates that the court did not consider independent enquiry or scrutiny to be necessary. Instead, the cases are uniformly approached with the attitude that the medical evidence is beyond question and that the appropriate model of inquiry is consensus-based. It is widely agreed that adversarial framework is inappropriate in these cases, because it is too combative and antagonistic. However, compromising adversarial processes means that courts must otherwise ensure that evidence is appropriately tested. This could include appointment of an intervenor or Independent Children's Lawyer. It is our belief that such an approach is inadequate.

While the *Family Court Act 1975* (Cth) s 68L explicitly provides for children and minors to be represented by an independent Children's Lawyer, an ICL has been appointed in only one of the eight cases concerning intersex children, *Re Sarah*.³¹ This is surprising given that Sarah was 17 years old at the time of the hearing,

²⁹ Garry Warne, 'My life of engagement with intersex issues: the getting of Wisdom' <https://www.dropbox.com/s/08apbkxw2neg02j/my_life_of_engagement_with_intersex_issues-warne-2013.pdf?dl=0>.

³⁰ *Re Sarah* [2014] FamCA 208.[16]

³¹ *Ibid*.

and was found to be Gillick competent. By contrast, in the cases *Re Lesley*,³² *Re Carla*³³ and *Re Sean and Russell*,³⁴ concerning very young children, no independent children's lawyer was appointed. In *Re Sean and Russell*, Murphy J provided a lengthy explanation for his decision which focussed on the consensus and lack of dispute regarding the proposed procedure. Similar reasons were relied on in *Re Lesley*. The possibility was not adverted to in *Re Carla*.

In five intersex cases before the Family Court, an intervenor or amicus was appointed by the court, usually the relevant state child welfare department. However, none of the intervenors or amici curiae opposed the application, sought to adduce other evidence, challenged any medical evidence or cross examined any of the medical witnesses. In other words, a commonality among all of the cases concerning intersex children is the lack of any challenge to the medical evidence, any testing of the evidence via cross-examination or any attempt to adduce contradictory evidence. This is concerning in many of the cases, where the medical evidence does not represent a consensus within the medical community and the clinical literature. Concerns expressed over decades by intersex adults and organisations, by dissenting clinical voices, and by human rights institutions have wrongly been disregarded. The lack of effective contradictor in every one of these cases has meant that contestable, unbalanced and selective evidence has gone unchallenged. This represents a significant deficiency in the ability of the Family Court to provide appropriate oversight and monitoring.

A further signal that the Family Court should not be tasked with oversight responsibility is that the judicial response to medical interventions undertaken on minors with variations of sex characteristics without court authorisation has ranged from indifference to active approval. In the earliest case of *Re A (A Child)*³⁵ heard in 1993, a medical witness deposed that A had undergone genital surgeries. This was quoted in the reasons for judgment, but no comment was made in the decision. Instead, Mushin J was highly critical of A's parents for failing to enforce compliance with the medical regime that had been determined by the medical team. Carla's genital surgeries are described with unmistakable approval as 'enhancements'.³⁶ Justice Tree in *Re Kaitlin* notes the decision to prescribe male hormones for Kaitlin without demur and describes the requirement of court approval as 'fanciful'.³⁷

In *Re Lesley*, knowledge that people who have been undergone medical interventions to alter sex characteristics have decried the treatment as damaging and harmful is dismissed as sensationalist:

In reaching the conclusion I am only too conscious of anecdotal accounts of individuals having gender reassignment procedures later in life, having great difficulty accepting the situation that has been thrust on them. On the medical evidence available that would not be indicated as likely

³² *Re Lesley (Special Medical Procedure)* [2008] FamCA 1226.

³³ *Re Carla (Medical Procedures)* [2016] FamCA (20 January 2016).

³⁴ *Re Sean and Russell (Special Medical Procedures)* [2010] FamCA 948.

³⁵ *Re A (A Child)* (1993) 16 Fam LR 715.

³⁶ *Re Carla (Medical Procedures)* [2016] FamCA (20 January 2016).

³⁷ *Re: Kaitlin* [2017] FamCA 83.

in Lesley's case. I note that many of the accounts are sensationalised in the media. I far prefer the evidence set out in the medical reports.³⁸

In *Re Carla*, Forrest J constructs a sense of urgency around the proposed procedures, and reveals profound disrespect for the right to autonomy and self-determination of the child:

The medical evidence recommends that the procedure be performed prior to Carla commencing puberty and supports the position that there is no reason to delay the procedure especially given that there are physical and psychological risks associated with such a delay and particularly given that it will be less psychologically traumatic for Carla if it is performed before she is able to understand the nature of the procedure.³⁹

For all of these reasons, the current mechanism of the Family Court exercising *parens patriae*-type of jurisdiction has not provided suitable protections for minors born with variations of sex characteristics.

The Family Court has failed to properly utilise its procedures in order to ensure that the best interests of intersex children have been thoroughly investigated and understood within the medical context, and within a human rights context where consensus on the need to protect the rights of children with intersex variations, and children with disabilities, is fully recognised.⁴⁰

3 Alternative Mechanisms

In Paragraph 9.107, the Discussion Paper sets out suggested options for reform including

- adoption of a more inquisitorial approach;
- introduction of multidisciplinary tribunals with expertise in medicine, psychology and social work to consider these matters;
- removing the jurisdiction from the Family Court and transferring it to an independent body, such as state or territory tribunals; or
- a total prohibition on sterilisation of girls with disabilities.

The discussion paper responds to these submissions by explaining that the ALRC considers that there is scope for improvement in the current approach to regulation of these procedures. This could be achieved by improvements to the operation of the welfare jurisdiction, transfer of the function to a more specialist body (such as a state or territory tribunal), or through direct regulation of the procedures.

³⁸ *Re Lesley (Special Medical Procedure)* [2008] FamCA 1226. [48]

³⁹ *Re Carla (Medical Procedures)* [2016] FamCA (20 January 2016) [18]

⁴⁰ United Nations Human Rights Office of the High Commissioner, 'End Violence and Harmful Medical Practices on Intersex Children and Adults, UN and Regional Experts Urge' (2016) <<https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E>>; Committee on the Elimination of Discrimination against Women, *Concluding Observations on the Eighth Periodic Report of Australia*, CEDAW/C/AUS/CO/8; Australian Human Rights Commission, 'Protecting the Human Rights of People Born with Variations in Sex Characteristics in the Context of Medical Interventions Consultation Paper' (2018).

IHRA submits that none of the suggested options is satisfactory for reasons that we have explained, and that we outline in more detail below. In line with the *Darlington Statement*, intersex human rights defenders call for effective oversight of medical interventions on children born with variations of sex characteristics. We call for lines between therapeutic and non-therapeutic interventions to be redrawn in a more appropriate place, between deferrable and non-deferrable irreversible interventions because distinctions between therapeutic and non-therapeutic interventions may remain unclear in some cases.

3.1 Legislative Prohibition of deferrable interventions

IHRA supports the introduction of legislative prohibition of deferrable interventions which alter the sex characteristics of infants and children undertaken before they develop capacity to consent on their own behalf. This commitment to hard law mechanisms may appear polemical or over-reaching. However, soft law mechanisms have been powerless to bring about cultural change within clinical settings or to impose effective restraints. Clinical narratives constructing intersex as a pathology have been highly resistant to efforts to disrupt and problematize the pathologising framework within medical culture. The medical paradigm has been able to effectively absorb and instrumentalize opposition, partially by echoing concerns in rhetorical literature. For example, the Victorian Department of Health's Decision-Making Principles for the care of intersex children offers strong rhetorical support for the concerns of intersex advocates and the international debate on the ethics of normalising surgeries;

The focus of concern is in cases where treatments for cosmetic effect are carried out for conditions that pose little or no physical risk to the patient (for example, to 'normalise' the person's body to make it look more typically male or female).⁴¹

Very often, public statements outline the ethical concerns in detail, and express support for those concerns.⁴² However, that support is not evident in clinical practice, as explained above.

It is clear that nothing short of legislative prohibition is likely to have an impact on a deeply entrenched, heavily medicalised paradigm which has proven stubbornly resistant to challenge or change.

The difficulty is with defining 'urgent non-deferrable medical necessity' with sufficient precision to prevent gaming of the criteria, but with flexibility and breadth necessary to ensure that minors are able to get treatment which meets their genuine needs and interests. Urgent non-deferrable medical necessity would include treatment necessitated by a serious threat to life or health. It may be impossible to provide further clarity in the abstract. However, the legislation should ensure that all medical interventions which are performed on the basis of urgent non-deferrable medical necessity are monitored, both pre- and post-facto, to evaluate and assess, from the perspective of human rights, whether such interventions were justified.

⁴¹ Victoria Department of Health, 'Decision-making principles for the care of infants, children and adolescents with intersex conditions' (2013).. 21

⁴² See, for example, Australasian Paediatric Endocrine Group, 'Submission to the Senate Inquiry Into Involuntary or Coerced Sterilization of People with Disabilities in Australia' (2013) (88)

3.2 Oversight by an Independent Body

IHRA supports the establishment of an independent body to determine whether or not medical interventions to modify the sex characteristics of children born with variations of sex characteristics and people with disabilities are necessary and non-deferrable. This same body should be tasked also with receiving and evaluating post facto notifications of details of all cases involving either minors or adults with supported decision-making where informed consent and/or urgent non-deferrable medical necessity have been asserted.

A grey zone exists between intersex variations and endosex (non-intersex) variation; between diagnoses defined at any time as “disorders of sex development” and those defined using other terms; and between variations of sex characteristics and other sex characteristics. The design of an oversight body should consider the implications of a situation where terms may be gamed, and where explicit rationales change over time while practices and procedures remain unchanged. To eliminate the possibility of gaming, and to ensure adherence and transparency, the independent oversight body must be notified, post facto (after the event), of details of all cases involving either minors or adults with supported decision-making where informed consent and/or urgent non-deferrable medical necessity have been asserted. Resourcing must be commensurate with this task.

An oversight body should be led by a human rights expert with meaningful and effective participation by intersex-led community organisations including IHRA and AISSGA, and disability representative organisations. The body must include clinical representatives with diverse perspectives, including mental health perspectives and perspectives gained from work with adults as well as children.

In considering non-deferrable medical necessity in cases of doubt, the pros and cons of medical treatment must be properly ventilated and considered, including the lifelong health, legal, ethical, sexual and human rights implications. Determination that treatment is non-deferrable and medically necessary must be premised on provision of all available medical evidence on necessity, timing, procedure, and evaluation of outcome of medical interventions. The state is obligated to provide all supports necessary for children and adults to give free and informed consent to medical intervention within Article 12 of the *Convention on the Rights of Persons with Disabilities* and General Comment 1 (Committee on the Rights of Persons with Disabilities 2014).

Where there is no clinical consensus, this must be disclosed. The oversight body, however constituted, must not be a substitute for consideration of human rights norms that have been clearly articulated by UN Treaty Bodies and other institutions. Where treatment violates the rights of the child, it must not take place. The primary purpose of an oversight mechanism is to ensure that the human rights of individuals subjected to medical interventions are respected. A model developed for the protection of people born with variations of sex characteristics may serve as a test case or model for the benefit of other populations, including children with intellectual and/or psychosocial disabilities, and others that are often subjected to “special medical procedures”.

The oversight body should not take the form of a multi-disciplinary tribunal steeped in the culture of medicalisation of disability and difference. Nor should jurisdiction be handed over to existing tribunals or new tribunals modelled on existing tribunals. The transfer of function to an independent body such as a

guardianship tribunal would present a significant risk that the tribunal would not operate within a human rights framework. Existing tribunals dealing, for example, with applications for sterilisation of disabled women have proved as incapable of operating from a human rights perspective as the Family Court. Guardianship laws and tribunals operate on the basis of outdated frameworks and principles. They are non-compliant with Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD) requiring equal recognition before the law. For example, while the CRPD moves from best interests to rights, will and preference as a child ages, and treats children with disability on the same basis as other children in this, NSW tribunals do not take this approach. Training of judges and tribunal members is not sufficient to address this. Instead, a human rights approach must be the primary framework within which decisions are made.

Furthermore, if such a transfer of function were recommended, it could only be effective if it operates on the basis of a legislated prohibition against deferrable interventions without individual consent.

3.3 Best interests Framework

The Senate Committee report in 2013 provided guidance on implementing a human rights-affirming framework for medical interventions on children born with variations in sex characteristics:

3.97 The evidence suggests that a human rights consistent framework ... must necessarily operate from a presumption in favour of maintaining the [child's bodily] status quo for as long as possible except where such a presumption would conflict with the child's best interests. A model that confers rights on third parties, through substitute decision making, before it guarantees the rights of the child, is likely to be a disproportionate limitation of the child's right to autonomy/self-determination.⁴³

However, the best interests test has been utilised to justify early and unnecessary medical interventions. In relation to *Re Carla*, Kelly and Smith report

Forrest J relied on the affidavit evidence of Carla's parents and her treating medical professionals to conclude that surgery was in Carla's best interests. In their affidavit, Carla's parents' stated that 'Carla acts as a girl' and does not identify as 'anything but female'.⁴⁴

The judge also determined that sterilisation was in the child's best interests for avoidance of risk of cancer. Kelly and Smith comment:

Based on the evidence provided to him, Forrest J approved the gonadectomy, finding it to be in Carla's best interests. Forrest J also approved 'such further or other necessary and consequential procedures to give effect to the treatment of Carla'. Beyond oestrogen treatment these 'consequential procedures' are not defined and for this reason, we are of

⁴³ Senate Community Affairs References Committee, Parliament of Australia, *Involuntary or Coerced Sterilisation of Intersex People in Australia* (2013).

⁴⁴ Fiona Kelly and Malcolm K. Smith, 'Should Court Authorisation be Required for Surgery on Intersex Children? A Critique of the Family Court Decision in *Re Carla*' (2017) 31(2) *Australian Journal of Family Law* 118.

the view that it was not actually possible to determine that a range of undefined procedures planned for some time in the future, are in Carla’s best interests (Kelly and Smith 2017).⁴⁵

They comment that, contrarily, in Family Court decisions regarding puberty blockers for transgender children, courts have determined that

at the time that hormone blockers are requested (typically 3–5 years before gender affirming hormones might be administered), it is not possible or appropriate to determine whether gender affirming hormone treatment will be in the child’s best interests (Kelly and Smith 2017).⁴⁶

It appears to this extent that the best interests of intersex children, and of transgender children, have not been treated in a commensurate manner. Kelly and Smith argue that the treatment in *Re: Carla* ‘sets a dangerous precedent’:

the medical evidence provided to the Court to justify surgery was incomplete and the reasoning and analysis concerning the therapeutic nature of the proposed surgery lacks rigour. In addition, a concerning aspect of Carla’s earlier medical care (undertaken prior to the application to the Family Court that was made by Carla’s parents in this case), was that the surgical interventions that occurred — which were described as purely cosmetic in nature — were made by the parents and health care team without Court approval. This runs contrary to the principles in *Marion’s Case* (Kelly and Smith 2017).⁴⁷

We fear that information provided to support parental decision-making may be similarly incomplete.

Kirsten Sandberg comments that psychosocial rationales have long been relied on as grounds for regarding surgery on infants as in a child’s best interests. However, she states that parents’ ‘interest in having a “normal” child may influence what they think is in their child’s best interests’ and physicians are similarly unable to ‘make a well-informed and impartial consideration of’ the child’s best interests’:

it is questionable if anybody else than the child itself is able to make an informed assessment of its best interests in this respect, both regarding the decision of whether or not to assign a sex, and not least, regarding what that sex should be. Consequently, even if one were to accept the assumption that the decision should be based on the best interests of the child, the decision would have to be postponed ... [and] the best interests of the child cannot override other rights under the CRC (K. Sandberg 2018).⁴⁸

⁴⁵ Ibid.

⁴⁶ Ibid.

⁴⁷ Ibid.

⁴⁸ Kirsten Sandberg, ‘Intersex Children and the UN Convention on the Rights of the Child’ in Anatol Dutta Jens Scherpe, and Tobias Helms (ed), *The Legal Status of Intersex Persons* (Intersentia, 2018) 514.

3.3.1 Best Interests and Human Rights – Family Law Act and International Human Rights Principles.

The difficulty is that the *Family Law Act 1975* (Cth) provides the relevant Australian legal framework, and Human Rights conventions and treaties have no formal status in law in Australia. This means that, although the treaties can be referred to in certain circumstances in interpreting legislation, the explicit words of a statute cannot be overridden by reference to human rights articles.

Principle 18 of the 2007 *Yogyakarta Principles* adopts the same principles in a call for protection from medical abuses to impose a gender identity:

[States shall] b) Take all necessary legislative, administrative and other measures to ensure that no child's body is irreversibly altered by medical procedures in an attempt to impose a gender identity without the full, free and informed consent of the child in accordance with the age and maturity of the child and guided by the principle that in all actions concerning children, the best interests of the child shall be a primary consideration; (Yogyakarta Principles 2017)

However, determinations of children's best interests in relation to medical interventions on intersex bodies have not met these principles. *Yogyakarta Principles* Principle 18 has proven inadequate. Indeed, as the UN Committee on the Rights of the Child has pointed out in the years since the *Yogyakarta Principles* were first adopted, the best interests principle can (and has been) manipulated to justify violations of the right to bodily integrity. Committee on the Rights of the Child. General Comment 14 'on the right of the child to have his or her best interests taken as a primary consideration' states:

34. The flexibility of the concept of the child's best interests allows it to be responsive to the situation of individual children and to evolve knowledge about child development. However, it may also leave room for manipulation; the concept of the child's best interests has been abused by Governments and other State authorities to justify racist policies (Committee on the Rights of the Child 2013).

The Committee on the Rights of the Child General Comment 13 on 'Article 19: The right of the child to freedom from all forms of violence' states that interpretations of best interests 'cannot be used to justify practices ... which conflict with the child's human dignity and right to physical integrity':

54. Article 3 (Best interests of the child): The Committee emphasizes that the interpretation of a child's best interests must be consistent with the whole Convention, including the obligation to protect children from all forms of violence. It cannot be used to justify practices, including corporal punishment and other forms of cruel or degrading punishment, which conflict with the child's human dignity and right to physical integrity. An adult's judgment of a child's best interests cannot override the obligation to respect all the child's rights under the Convention (Committee on the Rights of the Child 2011).

However the *Family Law Act 1975* (Cth) explicitly gives paramountcy to best interests. However, since the insertion of s 60B(4) which includes giving effect to the Convention on the Rights of the Child as an

object of the relevant Parts of the Act, the insights in General Comment 14 can at least inform the interpretation of best interests.

The UN Committee on Civil and Political Rights identified in General Comment 35 that the right to bodily integrity is derived from article 3 of the Universal Declaration of Human Rights; the right to life, liberty and security of the person:

2. Article 9 recognizes and protects both liberty of person and security of person. In the Universal Declaration of Human Rights, article 3 proclaims that everyone has the right to life, liberty and security of person. That is the first substantive right protected by the Universal Declaration, which indicates the profound importance of article 9 of the Covenant both for individuals and for society as a whole...

3. ... Security of person concerns freedom from injury to the body and the mind, or bodily and mental integrity... (Committee on Civil and Political Rights 2014)

In our view, the ‘best interests’ test has been misapplied in the Family Court and in clinical decision-making processes. State obligations in the *Yogyakarta Principles plus 10* Principle 32 address this issue, restricting the scope of situations where the best interests test applies and seeking to eliminate manipulation of the concept:

D) Bearing in mind the child’s right to life, non-discrimination, the best interests of the child, and respect for the child’s views, ensure that children are fully consulted and informed regarding any modifications to their sex characteristics necessary to avoid or remedy proven, serious physical harm, and ensure that any such modifications are consented to by the child concerned in a manner consistent with the child’s evolving capacity;

E) Ensure that the concept of the best interest of the child is not manipulated to justify practices that conflict with the child’s right to bodily integrity; (Yogyakarta Principles 2017)

3.4 Adopting an Inquisitorial Approach in the Welfare Jurisdiction

While some submissions support changes to the welfare jurisdiction to improve its effectiveness in monitoring medical interventions on intersex children, IHRA does not support these proposals. Historically, the welfare jurisdiction has been ineffective in protecting vulnerable children, including children with intersex variations and children with disabilities. For both cohorts, the Courts have acquiesced to sterilisation without adequate justification and without reference to human rights protections.

The legislative framework and professional culture of the Family Court Welfare jurisdiction is committed to the primacy of best interests in decision-making. However, as noted above, the best interests agenda has proven problematic in this domain.

The discussion paper identifies a recommendation by ICLC that the Family Court should adopt a more inquisitorial approach in Intersex cases. ICLC argue that this would help to

ensure judicial review is inclusive of relevant and contemporary specialist medical practice, current medical evidence, including contemporary medical research and guidelines would ensure the process was one whereby the applications are subject to thorough judicial scrutiny. (Submission 124, 11-12)

Unfortunately, this has not proven to follow from the adoption of an inquisitorial approach. As noted above, in five of the eight cases to date concerning intersex children, the court appointed an intervenor. This proved ineffectual in ensuring a rigorous and thorough examination of the issues. None of these intervenors tested or challenged the application or the medical evidence on any grounds. Nor did they introduce any evidence or cross examine any witnesses. The adoption of a more inquisitorial approach has facilitated the judicial failure to resist, challenge, question or critique the medicalised pathologising approach. In each of the eight cases to date, there has been a clear consensus among the parties supporting the applications.

As an example, we can consider the history behind the special medical jurisdiction, which was established in the High Court decision in *Marion's Case*. This case was preceded by four Australian cases which strongly challenged the medical framework in which sterilisation of girls and women with intellectual disabilities was normalised such that it escaped legal and ethical scrutiny.⁴⁹ In all five of these early cases, the litigation was initiated by a public interest group such as a disability advocacy service, and the Human Rights Commission acted as an Intervenor. The intervenor in each case sought to challenge the authority of the medical paradigm and to emphasise the human rights and broader social issues, including reframing disability as a social construct rather than as an individualised biological deficit requiring medical intervention. As a result of this context, each issue was strongly contested, thoroughly ventilated and challenged in great detail. Each of the hearings involved a detailed, deeply considered and careful analysis of the medical, social and political issues. The medical evidence adduced by each party reflected strongly held opposing views.

In *Re Jane*⁵⁰ for example, the Acting Public Advocate of the State of Victoria commenced injunctive proceedings⁵¹ seeking appointment as next friend of the child. The parents of Jane were Respondents in the proceedings. The Human Rights Commission intervened in the proceedings.⁵² Medical evidence was tendered on behalf of both parties and came from a range of medical specialists including Professor Bishop, a consultant obstetrician and gynaecologist; Dr L Reti, a consultant obstetrician and gynaecologist; Dr Glaser, a psychiatrist; Ms Sue Davies, a psychologist with the Office of the Intellectually Disabled; Dr Krupinska, a psychiatrist; and Dr Lupton, psychiatrist.⁵³ All of these cases, including *Marion's Case*, were hotly contested, providing the court with vying perspectives and

⁴⁹ *Re Jane* (1988) 94 FLR 1. 4-6; *Re a Teenager* (1988) 94 FLR 181 ; *Re Elizabeth* (1989) 96 FLR 248.; *Attorney-General (Qld) v Parents (Re S)* (1989) 98 FLR 41

⁵⁰ *Re Jane* (1988) 94 FLR 1.

⁵¹ *Guardianship and Administration Board Act 1986* (Vic) s16(1)(f) empowers the Public Advocate to represent interests of persons with a disability in such proceedings.

⁵² *Human Rights and Equal Opportunity Commission Act 1986* (Cth). S11(1)(o)

⁵³ *Re Jane* (1988) 94 FLR 1. 4-6

subjecting all the evidence to close testing and examination. It was this context that led to a paradigm shift in medico-legal attitudes to non-therapeutic sterilisation.

3.5 Additional Safeguards

3.5.1 Capacity and Gillick Competence

Capacity is a central issue in protecting the human rights of minors with disabilities and minors born with intersex variations. It is important that the ALRC and whatever body is tasked with monitoring medical interventions on minors take as their starting point the need to recognise and give effect to legal capacity of all individuals. Under Article 12 of the CRPD, persons with disabilities are entitled to recognition that they enjoy legal capacity on an equal basis with others in all aspects of life.

Furthermore, Article 12 requires that persons with disabilities are provided with access to the support they may require in exercising their legal capacity.

In Australia the capacity of minors to consent to or refuse medical treatment is referred to as 'Gillick-competence', named after the seminal English case in which the concept was developed. Gillick competence is a standard whereby minors can consent or refuse medical treatment if they possess 'a sufficient understanding and intelligence to enable him or her to understand fully what is proposed.'⁵⁴ Gillick competence describes a shifting, fluid understanding of capacity whereby a minor may have capacity for some decisions in some circumstances, but capacity is not static. Thus Gillick competence of minors can be bolstered and extended by measures to provide support in line with Article 12.

The dangers of capacity assessment are the likelihood that capacity of minors (and particularly minors with disabilities) will be underestimated, the general preference shown for functional approaches to legal capacity, the tendency to construct capacity as static rather than fluid and shifting, and the almost ubiquitous propensity to conflate legal capacity with mental capacity. As Steele and Beaupert observe,

The assumed relationship between mental incapacity and disability is commonly presented as objective, scientific and natural. Yet the self-evidence of the association between disability and mental incapacity has been contested in disability studies scholarship and disability rights activism.⁵⁵

Individuals, as well as parents and carers, need access to independent, resourced, affirmative peer support, and organisations providing systemic and individual advocacy. Intersex-led peer and advocacy organisations should be funded to develop information and staffing resources to support decision-making, just as disability organisations providing systemic and individual advocacy are resourced to support their population. These should include guides to the provision of information to parents and individuals within clinical settings.

The *Darlington Statement* includes demands in relation to peer support, in recognition of the importance it is for exercise of legal capacity. The *Darlington Statement* includes the following principles:

⁵⁴ *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 12 affirmed in *Secretary, Department of Health and Community Services v J.W.B. and S.M.B. (Marion's Case)* [1992] CLR 175.

⁵⁵

39. We recognise the **trauma and mental health concerns** caused by the unnecessary medicalisation of intersex people, as well as stigmatisation of intersex characteristics that has resulted in a legacy of isolation, secrecy and shame.
40. We recognise the fundamental importance and benefits of **affirmative peer support** for people born with variations of sex characteristics.
41. Our peer support organisations and other peer communities need resourcing and support to **build communities and networks** inclusive of all intersex people. No intersex person or parent of an intersex child should feel they are alone, irrespective of their bodily variation or the language they use.
42. We recognise the needs and lived experience of **youth**, and of people coming from varied **cultural and faith backgrounds**. We recognise these experiences as valid and legitimate.
43. We recognise the fundamental importance and benefits of **peer support for parents, caregivers, and families** of people with variations of sex characteristics. We recognise the importance and benefits of **peer support for friends, partners, and others** who support intersex people in their day-to-day lives.
44. **Peer support must be integrated** into human rights-based multi-disciplinary medical approaches, teams and services.
45. We call for **public, governmental, and philanthropic support** for funded, affirmative peer support.
46. We acknowledge that intersex people are the **experts** on our own lives and lived experience. Intersex people are experts in understanding the long term effects of medicalisation and medical interventions. (Androgen Insensitivity Syndrome Support Group Australia et al. 2017)

Rhetoric about the uniqueness of each case, and individualised decision-making acts against statements calling for access to peer support. Individualising decision-making suggests that family and individual needs are distinct; that families and individuals with different intersex variations do not share anything in common. It justifies their isolation; not putting families in contact with peers.

3.5.2 Supporting Decision-Making by Minors

We believe that independent and affirmative peer support, and advocates working on systemic and individual issues, should be integrated into multidisciplinary teams. Medical sociologist and former AIS-DSD president Georgiann Davis states:

What my research and experience with intersex organizations in the U.S. reveal is that there is often resistance to organizational change by organizational members who have been psychologically and unethically harmed by medical professionals who frame intersex as a medical emergency rather than a natural bodily variation (Davis 2018).⁵⁶

⁵⁶ Georgiann Davis, 'Re: Resistance to Organizational Change' on (11 September 2018.).

In the period 2014-2015, the AIS-DSD Support Group opened up to intersex people of all genders, and parents, through addressing concerns that individuals needed space to connect with similarly situated individuals.

Parents may not wish for a child's sex or gender to be questioned, especially where these might call a child's history of medical interventions into doubt. Eric and Stephani Lohman, parents of a child with CAH, have described how:

We quickly found that parent and advocacy groups associated with our child's specific condition were deficient sources of information on raising a surgery-free child. This is partly due, we suspect, to the fact that several prominent pediatric urological surgeons are affiliated directly... The general impression we got from these organizations was that, if we wanted avoid surgery they supported that choice, so long as we kept that decision to ourselves. We were unable to find any other parents on social media or otherwise that had children born with similar conditions who had opted against a cosmetic genital procedure in infancy (we have since found fewer than ten families, almost all of whom choose to remain discreet about their decision).⁵⁷

There is a risk that parent-led groups may, then, be dominated by narrow clinical perspectives and accompanied by fears, often driven by clinical narratives that lack evidence and, in a situation described by the Lohman's, proposing not 'surgery or no surgery' but one type of surgery or another,⁵⁸ Parents may also be led to fear straw men arguments, such as the idea that intersex is an identity category, and the idea that medical interventions can prevent their child from forming such an identity.

3.5.3 Protecting the Human Rights of all Minors

The operation of the welfare jurisdiction of the Family Court has largely impacted minors who are transgender, intersex, or have a disability. Since the decision in 2017 in *Re Kelvin*, there has been pressure towards removing decision-making out of the court. This has been echoed in a number of cases such as *Re Carla*. The move away from court authorisation for transgender minors marks a progressive, enlightened and rights-oriented attitude to transgender people that reflects best international practice in both medical and human rights terms. However, the decision in *Re Carla*, which also moved away from court authorisation for intersex minors is deeply problematic. It ignores the chronic and widespread breaches of human rights of children with intersex variations. Similarly, efforts to remove decisions to sterilise intellectually disable girls from oversight processes do not represent progress or enlightenment.

What is important across all three cohorts is respect for legal capacity and an overarching framework that people who are affected by medical interventions must want them and be able to consent to them. Where there is capacity, then consent and autonomy should be respected and given effect to.

⁵⁷ Lohman and Lohman, above n , 17-18

⁵⁸ Ibid. 86-90

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